

**TEACH Summer School**

*Bucharest, Romania*

*27-30 June, 2017*



***'New Horizons in  
Personalised Medicine'***

***Report 2017***



**European Alliance for  
Personalised Medicine**

# TEACH Summer School

Bucharest, Romania

27-30 June, 2017

## Introduction

It was wonderful to welcome delegates and the faculty to Bucharest, the capital of Romania, and at what was another major event for personalised medicine taking place in eastern Europe.

As co-chair and executive director of the European Alliance for Personalised Medicine, we were delighted that our SMART Outreach programme dove-tailed perfectly with the second Summer School, the first edition of which was held in Cascais, Portugal, in 2016.

'SMART' stands for Smaller Member states And Regions Together, so it is important to the Alliance that we hold events, not just in the bigger countries of the EU, but also in less big but equally forward-looking ones, too.

These Summer Schools are primarily about raising awareness and increasing knowledge of personalised medicine. Education in this area is paramount, if we are all to make the most of the incredible science that has emerged and is continuing to move forward with lightning speed.

We call these schools by the acronym TEACH, which stands for Training and Education for Advanced Clinicians and HCPs, or healthcare professionals. The goal is to bring young HCPs up-to-date with developments in this exciting new field.

As the title of the event was 'New Horizons in Personalised Medicine', among other aspects, the Summer School provided a highly interactive forum for sharing ideas for innovation, and practicing communication skills.

It allowed attendees to enhance their knowledge of personalised medicine and its potential, as well as offering feedback about the priorities we should be zooming in on down the line.

In the changing world of healthcare in Europe, which of course includes the exciting new developments in personalised medicine, the ongoing education of healthcare professionals has, so far, been under-emphasised.

The true potential of all of this fantastic new science, built

around genetic profiling and individual DNA, will never be fully realised unless front-line clinicians have the knowledge and understanding to exploit it.

Not only that, but relationships between healthcare professionals and patients will be key.

The landmark Luxembourg Presidency Council Conclusions on access to personalised medicine saw the Grand Duchy's health minister, Lydia Mutsch, explain that the exciting field of personalised medicine is, and should be, all about the patients.

It offers the opportunity for them to be seen not merely as passive recipients of care but as participants, partners and even guides in their own healthcare.

She added that one important goal should be giving clinicians better tools to treat and inform their patients and allow HCPs a better understanding of their patients' needs.

We wholeheartedly agree, as does every stakeholder in EAPM, including patient groups.

Health is all about patients and potential patients – almost 500 million across the EU's current 28 Member States.

The EU population is living longer, and is suffering much more from co-morbidities, basically several diseases at the same time. Resources are being stretched. In all countries, not just the less wealthy ones.

Yet patients are also better-informed than they have even been, although this is a double-edged sword in that too many so-called 'facts' on the internet can send self-diagnosis in entirely the wrong direction.

Despite their expanded involvement in decision making, it remains the case that patients also need to be more health literate, and attendees at the Summer School are key in that regard.

Governments, meanwhile, have to try harder. And we are all working on that!

There is, of course, a debate about how much 'power' a



David Byrne,  
Co-chair,  
EAPM



non-expert patient should actually have, and there is clearly a communication gap between the healthcare professional and the patient in many cases.

Patients don't always ask the right questions, and many doctors are unforthcoming unless asked specifically.

Yet personalised medicine aims to put the patient right at the centre of his or her own healthcare, and that means taking decisions in concert with doctors, nurses and surgeons.

Generally speaking, each healthcare system within the EU features the coming-together of one set of citizens in need of diagnosis and treatment and another set entrusted to deliver it.

This trust is based upon a blend of technical competence and service orientation and is steered by ethical commitment and social accountability, which forms the essence of reliable and professional healthcare.

Developing such a blend requires lengthy education of healthcare professionals and, consequently, a substantial investment by policy makers and society.

Let us be clear, this issue of education of HCPs is a major one. A great degree of up-skilling is already required and, to keep pace with the science, this must be ongoing.

Europe must ensure that no patient is denied a suitable, virtually tailor-made treatment due to a lack of knowledge or understanding on behalf of the HCP treating and diagnosing him or her.

Given the advances in personalised medicine in recent years, there is now a need to reform how healthcare is delivered to the more technology-aware patient.

Obviously, one way to achieve that goal is through the education and training of healthcare professionals. These summer schools are just the beginning.

On education generally, EAPM has already called for action at EU level, saying that, by the year 2020, the European Union should support the development of a Europe-wide education and training of HCPs curriculum for the personalised medicine era.

We in the Alliance also believe that the EU should subsequently facilitate the development of an Education and Training Strategy for HCPs in personalised medicine.

We are working hard to promote dialogues, encourage the required platform and, as stated, calling for swift EU action. Meanwhile, we are playing our part, as are all attendees and faculty, with our annual Summer School.

**David Byrne, Co-Chair, EAPM**  
**Denis Horgan, Executive Director, EAPM**

Giovanni Codacci-Pisanelli,  
Assistant Professor of Medical Oncology,  
University of Rome "La Sapienza"



## Background

The concept of personalised (or precision) medicine was brought into the public agenda, on a global scale, in January 2015 by former US President Barack Obama.

In the State of the Union address, Obama launched the Precision Medicine Initiative, whose goal is "the development of the means of disease prevention and treatment, which takes into account people's individual variations in genes, living environment, and lifestyle".

Personalised medicine, as we know, is based on the developments in the field of genome sequencing, biomedical technologies, and the ability to analyse and store medical data. All of these components are vital.

In Europe, the Council of the European Union, on 7th December 2015, granted pan-community policy recognition for "personalised medicine for patients", placing the theme among the EU priorities for the next decade and inviting the Member States and the European Commission to engage in reaching its full potential.

This was done through the Council Conclusions of the then-presidency of the EU, Luxembourg. Various health issues will also be taken up (especially concerning data) by the Estonian presidency, which took over on 1 July.

Personalised medicine aims to give the right treatment to the right patient at the right time. This represents a paradigm shift from the classical "one-size-fits-all" approach. Oncology, haematology and infectious diseases all benefit from the specific approach to personalised medicine.

Several diagnostic tests, medicines and personalised IT solutions have already been approved for use in the US and EU. Last year, 27% of newly approved drugs in the US were personalised drugs, and half of them are dedicated to the treatment of cancer. Data confirms that the trend began in 2014, when the proportion of personalised drugs first exceeded 20%.

Things are moving fast.

## Summer School sessions

### Plenary Session 1

#### ***Precision medicine in prevention and early diagnosis of cancer***

**Presented by Giovanni Codacci-Pisanelli, M.D.; Ph. D.**  
*Assistant Professor of Medical Oncology, University of Rome "La Sapienza"*

The progress obtained in recent years in the war against cancer is based on several weapons: more precise surgery, more sophisticated radiotherapy, more effective chemotherapy, more stimulating immunotherapy, and more early detection.

But more is not always better. The controversy on prostate cancer screening using PSA measurement is the best illustration of how "more diagnosis" is not a sufficient goal.

We must distinguish lethal and indolent forms of cancer that may develop in the same organ: the genetic characterisation of tumour cells is providing very interesting data in this sense. Detailed genetic analysis can be performed on very small tissue samples and even on circulating nucleic acids extracted from plasma.

The aim is to identify "more" tumours, but to adapt treatment (and its inevitable consequences) on the basis of real aggressiveness.

Cancer prevention is still largely unaccomplished: if we just consider how many people still smoke despite compelling evidence of the damages it causes, and not only cancer.

The identification of genes that predispose to cancer development resulted in effective forms of surgical prevention, and several clinical trials to identify preventive medical treatments are under way.

We must obtain more precise information to determine the real risks associated with the different mutations of the same gene and to identify genes linked to familiar forms that are



# TEACH Summer School

Bucharest, Romania

27-30 June, 2017



Emil Plesea, Secretary of Romanian Division of International Academy of Pathology

not caused by known damages. Personalised medicine is growing in all its aspects: precise treatments, precise prediction of toxicity, precise prevision of tumour behaviour, precise identification of persons at risk of cancer. There is great deal of data, and it must be used with competence.

## Plenary Session 2

### ***Monoclonal Antibodies to identify/ trigger cell surface targets***

**Presented by Emil Plesea, Secretary of Romanian Division of International Academy of Pathology**

Immunohistochemistry (IHC) of a tumoral tissue has been the cornerstone of protein-based cancer marker studies for several decades.

One essential purpose of IHC, beyond the confirmation of tumor diagnosis, is to provide useful prognostic information and even predict responsiveness to chemotherapy or monoclonal antibodies.

The presentation explored the role of immunohistochemistry in the fast-moving landscape of personalised medicine.

## Plenary session 3

### ***The following shows a prime example of the interactive nature of the entire Summer School:***

#### ***Communication in consultations***

This interactive session allowed attendees to watch and comment on a difficult clinical consultation presented as a role-play with a real clinician, but with actors playing the parts of patient and partner.

The consultation was undertaken to a pre-planned scenario

but unscripted to simulate as closely as possible a real clinical event.

Audience members were able to identify elements of good communication that have the effect of improving the outcome of the consultation and also propose for discussion alternative approaches to the conversation between clinician and patient/partner.

These insights may inform the future practice of clinicians but may also indicate means by which patients/patient advocates can engage more fruitfully with clinicians.

The highly interactive format allowed participants to explore the means by which difficult conversations take place in a clinical setting, both by watching an experienced clinician addressing the issues and by proposing alternative approaches to the role-play performers and receiving their feedback in role.

#### **Communication workshops**

Meanwhile, communication workshops took place with the intention of raising awareness of the importance of good communication between clinicians and patients using a highly interactive format.

The first part of the workshop asked the audience to propose topics of conversations from clinical consultations that they have personally found especially difficult or emotionally demanding, turning the broad issue into a realistic clinical scenario.

The approach exploring the difficulties in communication then involved allocating the role of the clinician to one of the actors and that of the patient to the other.

With some briefing by the delegates, the actors embarked on 'playing out' the consultation, but substantial difficulties

# TEACH Summer School

Bucharest, Romania

27-30 June, 2017



involved in delivering the message emerged and a period of facilitated coaching by the delegates ensued.

Armed with their suggestions, a second attempt at the consultation began. A final version of the consultation

incorporating the delegates' contributions resulted in a much-improved conversation between 'clinician' and 'patient'.

Below is an example of a scenario:

**The Scenario set out the case study within the communication skills workshops.**

**The patient, Mrs M, had been diagnosed with CML two weeks previously. She is aged 59 years and works in an insurance company. She has three children and two grandchildren.**

**Mrs M has no previous history of cardiovascular disease, no hypertension and no metabolic problems. She had surgery for hallus valgus in January this year and has noticed that the WBC already showed hyperleucocytosis, but this was not mentioned by the surgeon. The recent WBC assessment was performed due to asthenia. Bone marrow aspiration showed a hypercellular bone marrow, without excess of blasts, the t(9;22) was evidenced on cytogenetics with a BCR-ABL transcript in blood (M-BCR). No splenomegaly was found on physical examination.**

**Final diagnosis was CML in chronic phase, Low Sokal score. Mrs M was already told that the diagnosis of CML was highly suspected, and she is now waiting for a confirmation. She had searched on the internet and found that imatinib may no longer be the right TKI to treat CML.**

**During the consultation, it was necessary to explain to Mrs M what CML means, the effect of TKIs on CML, the choice between imatinib and other options.**

**One of those options is to participate in a randomised clinical trial comparing nilotinib first line to nilotinib with pegylated interferon.**



# TEACH Summer School

Bucharest, Romania

27-30 June, 2017



Marius Geanta,  
President, Center for  
Innovation in Medicine

## Plenary Session 4

### **Liquid Biopsy: technologies and application in lung cancer.**

**Presented by Prof. Mario Pazzagli, University of Florence, Italy**

Liquid biopsies are non-invasive blood diagnostic tests that detect circulating tumour cells (CTCs) and/or fragments of tumour DNA that are shed into the blood from the primary tumour and from metastatic sites.

This approach can have an important diagnostic and treatment implication that can transform clinical oncology practice and is an example of personalised medicine.

Whereas tumour genome sequencing is already central to inform treatment decisions and the management of oncological patients, the liquid biopsy may represent the non-invasive approach to monitor tumour genomic changes in real time.

This will allow clinicians to ensure that the therapy they have selected, based on a particular molecular target, remains relevant and eventually observe the emergence of any resistance such as the T790M mutation in lung cancer patients.

Eventually it will be possible to observe if any new molecular targets appear that could be suitable for different treatment. All this could help to provide patients with the

right treatment for the right target without delay.

Liquid biopsies also present us with a unique opportunity to move forward with our understanding of metastatic disease development and they may help to identify signalling pathways involved in cell invasiveness and metastatic competence.

These tests also have the possibility to be used in screening programmes at least for some kind of cancer. At the end the liquid biopsy can revolutionise cancer care, providing clinicians with rapid access to information on a molecular level at diagnosis, thereby optimising treatment choices.

### **Prevention or screening on tobacco control and lung cancer**

**Presented by Florin Mihaltan, School of General Medicine, Carol Davila University of Medicine and Pharmacy, Bucharest, Romania**

Smoking is a main cause of lung cancer and many other respiratory and cardio vascular diseases. For any country, even if it's a country with a low, middle or high health budget, a challenging problem remains to allocate revenue for prevention action or screening campaigns .

This session looked at the impact of such strategies and their consequences. It included arguments covering initiatives for prevention of smoking in children and teenagers, using Member State examples .

# TEACH Summer School

Bucharest, Romania

27-30 June, 2017

Frank Jorgensen,  
EAHP and  
hospital pharmacist



Steve Johnson, Taunton UK;  
Deborah Manship, Role Call;  
Sheila Tait, Role Call





# TEACH Summer School

Bucharest, Romania

27-30 June, 2017

## Evening Lecture

### ***“Curiosity, Serendipity and the Scientific Mindset – Observations of an Immunobiologist”***

**Presented by Richard J. Ablin**, Professor, University of Arizona College of Medicine

In “observations of an immunobiologist”, we’ve witnessed a vernacular transition from what we used to refer to as “basic- and clinically-applied immunology” to “translational immunology”, for example, immunotherapy (immuno-oncology).

But is there a difference? In today’s society, there are individuals who become experts and in some cases “reinvent the wheel” providing new names and acronyms portending to new and exciting things to come.

There are all kinds of new tools – from smartphones and iPads to gene sequencers to powerful microscopes; combine this with data mining and visualisations, and the laboratory of today is very different than it was 35 years ago.

But, the overarching principles remain the same. One needs a “scientific mindset”, one needs to question ‘why’ and go and seek the answers through the scientific method of research and observations.

Ablin’s research and observations have spanned a variety of immunologically-mediated phenomena. In the course thereof, through scientific curiosity and never stopping to ask ‘why’, and in concert with serendipity, what were initially thought of as disparate bits of information, have provided unique insights connecting several fundamental biological phenomena of health and disease.

## Plenary Session 5

### ***The Role of Data Analytics in Precision Medicine***

**Presented by Jonny Hancox**, Intel

In his talk, Hancox set out to show how data analytics in all its various guises, such as Data Science, Artificial Intelligence and Deep Learning, is starting to have an impact on the way that medicine is practiced and how its progression looks set to have a transformative effect on personalised medicine.

Citing recent examples in which Big Data analytics applied to internet searches have been used to reveal links between opioid overdoses, coronary heart disease and drug interactions, he suggested that this phenomenon is likely to become more commonplace in the coming years.

One of the mainstays of precision medicine; genomics, is underpinned by our ability to analyse huge volumes of data

at speed. Since the first human genome was sequenced in 2003, huge strides have been made not only in the technology to acquire the sequencing data but also the algorithms that reduce the terabyte-level raw sequences to megabyte-level patient-specific variants.

Even so, huge efforts remain to allow patients to be sequenced in a clinically-relevant timeframe (from days to minutes). Intel and other organisations, such as the Broad Institute in the US, lead this attempt to heft personalised medicine from research to routine clinical practice.

However, genomics is only one dimension in a more complex matrix of information that includes medical images, unstructured patient records, social media data and, in the future, remote body sensing data. It is only when this data is analysed in its fullest context that its full value can emerge.

For example, when making a clinical diagnosis, genetic data on its own is only of use for certain types of inherited disorders. For most other scenarios, a patient’s clinical history is an essential part of the data needed to formulate a diagnosis and determine the most appropriate treatment.

In the field of drug discovery, the ability to use previous compound testing results to predict new drug candidates has the potential to reduce expensive drug trial failures by prioritising those compounds with the best chances of success. Machine learning can infer missing data points by predicting most likely outcomes given results from compounds with the most similar characteristics. This sort of experimentation and extrapolation within a virtual world is an emerging trend in many areas of science.

For most cancers, tissue biopsy is still the gold standard for accurate diagnosis. Traditionally this has been accomplished by a pathologist reviewing a series of prepared samples under a microscope. For effective treatment of cancer, it is important that tumours are graded accurately and achieving objective grading can time-consuming and difficult.

The latest trend in medical imaging analytics is to use a branch of machine learning known as Deep Learning, which has proved immensely powerful at a range of image-interpretation tasks such as classifying and segmenting images. The University of Warwick’s Tissue Image Analytics Lab have teamed up with Intel to develop a software solution that can be trained to recognise various types of nuclei pertinent to the grading of cancer. This type of solution is going to have an impact on clinical workflows and is likely to disrupt the traditional diagnosis process.

Society doesn’t like change but it is important that the emerging generation of doctors are aware of the huge potential that today’s Data Analytics has. If doctors can work with technologists, new technologies could have a hugely beneficial impact on the lives of patients around the world.

# TEACH Summer School

Bucharest, Romania

27-30 June, 2017



With a growing and ageing population and a limited supply of doctors, it seems likely that data analytics could play an important role in filling the gap between what we'd like to do and what is possible using humans alone.

## **Technology for development**

**Presented by Dan Gârlau, Oracle**

Large and complex data sets are becoming the norm in the organisations that provide healthcare services. This is supported by the adoption of electronic medical records, advances in medical imaging, genetic research and the use of huge databases in pharmaceutical studies.

By using data mining tools on data series from a large number of patients, medical research emphasises more precisely the causes of certain diseases and the options for prevention, diagnosis and treatment.

Electronic health records were designed to include the full medical history of the patient going back a long.

These records may include a wide range of data in detailed or summarised format, as well as the medical history, treatments and allergies, level of immunity, results of some tests, radiological images, demographic data and invoicing data for medical services provided to the patient.

The use of Big Data for healthcare services is equally an opportunity to improve the quality of healthcare and to optimise costs.

Starting from the standardisation of the electronic health chart, the Californian consortium of healthcare services, Kaiser Permanente built a multidimensional Big Data structure which records the information of the patients admitted and discharged, pharmacy data, accounting data, and from other groups from the organisation which use software applications for decision support.

These departments have to analyse a multitude of data at the same time: treatments, demographic data, results of lab tests, prescriptions, medical plans and payrolls.

By integrating this disparate information together, the decision support system of the organisation allows physicians and nurses to understand the complete history of the patients and to choose the right treatment.

Kaiser Permanente maintains a virtual data warehouse with standardised files.

The content and data areas usually required for research studies are provided to the users. At the same time, data dictionaries are created for each content area specifying the format for each element, and variable names, variable tags, extended definitions, values for codes and labels.

*Following the above presentations, there was a session on communications using role-play and workshops, as described earlier in this report.*



# TEACH Summer School

Bucharest, Romania

27-30 June, 2017



Richard Ablin,  
Professor, University of  
Arizona College of Medicine

## Plenary Session 7

### ***Biomarkers and personalised medicine Molecular tumour profiling and upcoming biomarkers: Will they help to deliver personalised medicine?***

**Presented by Beata Jagielska, Maria Skłodowska-Curie Memorial Cancer Center and Institute of Oncology; Department of Oncological Diagnostic, Cardio-Oncology and Palliative Care, Warsaw, Poland**

Melanomas are very aggressive and heterogenous diseases. The application of modern technologies for the treatment of melanomas has greatly improved the melanoma patients' outcomes.

BRAF mutation and their mutually exclusive occurrence with NRAS mutations, allows us to apply a new division of tumours. The oncogenic mutations in BRAF were present in nearly 70% of cutaneous melanoma tumours identified by investigators in 2002.

Since then, numerous inhibitors of BRAF and its downstream targets, including MEK and ERK, have been developed which show preclinical and clinical benefit.

Treatment of melanoma patients based on the two BRAF inhibitors (vemurafenib, dabrafenib) or the MEK inhibitor trametinib is associated with improved clinical benefit compared with treatment with standard chemotherapy.

Most patients have evidence of disease progression within 6-8 months after initial therapy with the BRAF and the MEK inhibitors. The mechanisms of resistance are probably related to activation of reactivating the MAP kinase pathway which provides some strategies on the way the resistance may be overcome.

The application the complex molecularly target therapy as a new strategy of treatment allows us to break resistance to the treatment. It is likely that a number of other strategies will be pursued over the coming years.

### ***Personalised Immuno-Oncology***

**Presented by Richard J. Ablin, Professor, University of Arizona College of Medicine**

A paradigm shift in the last few years toward immune-based therapies has dramatically altered the treatment landscape in oncology. Cancer immunotherapy, ergo, immuno-oncology, has provided objective responses in a variety of malignancies.

However, response rates have been low and regressions few and/or incomplete. The use of immunoprofiling ("immunostaging") to predict clinical responses toward selecting the right patient for the right immunotherapy - personalised immune-oncology, in combination with synergistic immunomodulators - may result in long-term benefit.

# TEACH Summer School

Bucharest, Romania

27-30 June, 2017

## Plenary Session 8

### **Pharmacokinetics - what's clinically relevant in haemophilia treatment?**

**Presented by Johannes Rischewski**, Paediatric Haemato-oncology and Paediatric Haemophilia Centre, Lucerne, University of Bale, Switzerland

A whole range of factor replacement products is currently available, and a relevant quantum will soon become available for the treatment of patients with bleeding disorders.

Product characteristics have to be compared using two categories: clinical benefit, which should be judged on the basis of clinical outcome parameters, and pharmacological differences.

A pharmacologically positive attribute does not necessarily translate into a relevant clinical benefit, and reasons for the clinical superiority of a product are not necessarily directly inferable from pharmacological parameters.

However, for a clinician, it is crucial to understand pharmacological and pharmacokinetic terms to detect potential advantages, drawbacks and pitfalls, and to be able to judge whether published data should have relevance in clinical decision processes, e.g. pro or contra a new factor replacement opportunity for a given patient.

The presentation aimed to make pharmacokinetic terms more accessible. Recovery, clearance, AUC (area under the curve), trough level and half-life were explained, and the effects of dose modifications and half-life extensions were discussed.

Finally, examples of published data were analysed, to flag up clinically important issues for decision processes.

## Plenary Session 9

### **Targeted sequencing in key oncogenes simultaneously as a base for precision oncology by Illumina NGS bench top sequencers**

**Presented by Theodor Zamfirov**, Illumina/Elta 90 Medical Research

The presentation included basic principals in Next Generation Sequencing. It highlighted the useful and

comprehensive information which sequencing is giving, compared to Real Time PCR used routinely today for diagnostics in targeted therapies, and more.

## Genomics as a Tool for Precision Therapeutics in epilepsy

**Presented by Dana Craiu**, Professor of Pediatric Neurology, MD, Ph.D., "Carol Davila" University of Medicine Bucharest, Department of Clinical Neurosciences, Pediatric Neurology Discipline II, Alexandru Obregia Hospital, Bucharest

Progress in genetic research was soon followed by immediate genetic testing in the clinical area. Why would we perform genetic testing in epilepsy since it is time consuming and costly?

First, because finding a diagnosis may provide prognostic information; second, for genetic advice and secondary disease prevention, but also for potential impact on treatment choice. This is important especially for some refractory epilepsies in which genetic diagnosis may guide treatment and improve epilepsy and cognition.

Avoiding adverse effects and severe adverse effects of drugs may be a clinical utilisation of genetic analysis along the road of personalised medicine

It is well-known that same drugs may have a different efficacy and also different adverse effects on different patients treated for the same type of epilepsy.

This is due to genetic differences in their pharmacogenetics. It is well-known today that some populations with the particular HLA-A\*31:01 genotype are at high risk of serious skin reactions to Carbamazepine.

It is an indication today in the RCP of carbamazepine that this HLA should be tested before using the drug in the populations at risk, thereby preventing allergies to Carbamazepine.

Citizens with HLA-B\*1502 are at higher risk for Stevens Johnson Syndrome (SJS) and testing them may avoid important morbidity and mortality due to SJS.

Some disorders are treatable, inherited metabolic epilepsies with very simple and effective treatment and this should not be missed, such as the pyridoxine-dependent epilepsy caused by ALDH7A1 mutations.





# TEACH Summer School

Bucharest, Romania

27-30 June, 2017



Denis Horgan,  
Executive Director,  
EAPM

In other epilepsies there are drugs that should be avoided and others which should be used. For example, in SCN1A epilepsies, lamotrigine and phenytoin should be avoided and stiripentol should be used.

In other situations (for example PCDH19), treatment may be suggested due to observational studies, but prospective trials should be performed.

And there are diseases where there is a hope for precision medicine, in the case of treatment based on physiopathological mechanisms, such as TSC (tuberous sclerosis complex) and DEPDC5 and other mTORpathies, including focal cortical dysplasia.

Multidisciplinary approaches involving consultations with geneticists may help in determining genetic-based approaches in the treatment of such patients

## Conclusions

Aside from producing a new batch of alumni from the Summer School, who were all very happy that they had attended, we significantly upped the numbers from 2016.

These Summer Schools certainly deepen the work of EAPM and we will bring issues that the attendees highlighted - such as barriers and enablers - to the attention of policy makers, as ever. It is not only the alumni that learn a lot at these events, the Alliance and the faculty expand their knowledge too in a highly interactive two-way street.

One of many key points of recognition that emerged is the issue of HCP migration from smaller, less wealthy Member States to the larger and wealthier ones. Attendees agreed that the EU should do much more to remedy a situation that will become unsustainable down the line.

Among other lessons that we can all take forward into next year's School include additions to the curriculum as follows:

- We will ensure that there will be more of the highly successful communication role-plays at next year's event - and already three Member States have already expressed an interest in hosting it.

- There will be more multidisciplinary sessions, in order to see how different HCPs interpret various scenarios.

- We will introduce extended Q&A opportunities, alongside more breakout sessions during the course of the week.

Generally, in the sphere of personalised medicine, it is clear that part of what is required going forward is a long-term approach to education to ensure the translation of new therapies from laboratories to patients.

This means that all HCPs in close contact with patients or their patients' families need to be up-to-date with the current aspects of personalised medicine and its latest breakthroughs in order to better understand their patients' concerns.

Like the first, this second Summer School aimed to support the endeavours EAPM's stakeholders to set up a Continuous Educational Programme on personalised medicine.

It has to be recognised that the patient is at the centre of his or her own treatment and health-related decisions, and relevant skills need to be developed accordingly.

After two Summer Schools, EAPM and the faculty are now even more convinced that an improvement in such skills among HCPs is vital to giving the right treatment to the right patient at the right time - our ultimate aim.

Last but not least, EAPM would like to extend its gratitude to all of the faculty and attendees who, together, made this Summer School in Bucharest a great success. We look forward to achieving even more in summer 2018.



# European Alliance for Personalised Medicine

## About EAPM

The European Alliance for Personalised Medicine (EAPM) , launched in March 2012, brings together European healthcare experts and patient advocates involved with major chronic diseases.

The aim is to improve patient care by accelerating the development, delivery and uptake of personalised medicine and diagnostics, through consensus.

As the European discussion on personalised medicine gathers pace. EAPM is a response to the need for wider understanding of priorities and a more integrated approach among distinct lay and professional stakeholders.

The mix of EAPM members provides extensive scientific, clinical, caring and training expertise in personalised medicine and diagnostics, across patient groups, academia, health professionals and industry. Relevant departments of the European Commission have observer status, as does the EMA.

EAPM is funded by its members.

*Contact: Denis Horgan  
EAPM Executive Director  
Avenue de l'Armee/Legerlaan 10, 1040 Brussels  
Tel: + 32 4725 35 104  
Website: [www.euapm.eu](http://www.euapm.eu)*



**Special thanks to:**

**The Romanian Alliance for Personalised Medicine and their team.**